

Patient Panel Newsletter

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Recent CEBD Research Awards

We're really pleased to be able to let you know about a number of new funding awards as outlined below. It's really encouraging to see both the amount of independent funding (almost £1million) and the breadth of skin conditions involved, many of which have been under-researched previously. A huge thank you to all the CEBD Patient Panel members who have taken part in the development of these projects, most of who will continue to be key research partners as the work progresses.

THESEUS—this study has been funded by a National Institute for Health Research (NIHR) Commissioned Call on hidradentitis suppurativa (HS) and will investigate what the best treatment options are for HS when first line treatments fail to work. The £600K 3 year award is a major step forward for independent research into this painful and disabling condition. The project will be led by Dr John Ingram (Cardiff) and patients and carers from the patient support group the [HS Trust](#) have been instrumental in driving this work forward.

Blistering skin conditions—the project we mentioned in Issue 10 of the newsletter using large GP databases to identify patients affected by the blistering skin disorders bullous pemphigoid and pemphigus vulgaris has received confirmation of £150K funding from the NIHR Research for Patient Benefit Scheme (RfPB). Co-ordinated by Dr Sonia Ratib (Nottingham), this work will take place over the next two years alongside a Priority Setting Partnership (funded by a £8.5K award from Nottingham University Hospitals Trust) . Combined these two projects will inform future clinical trials.

Vitiligo—a £66K award from the NIHR RfPB scheme has been made to Dr Jonathan Batchelor (Nottingham/Kent) to further develop and evaluate the [Vitiligo Noticeability Scale](#) that was used as part of [the Hi-Light study](#). This patient-reported scale is used to assess the cosmetic acceptability of response to treatments for vitiligo.

Eczema—Dr Bob Boyle (Nottingham/London) has been successful in obtaining further funding (£150K from the NIHR RfPB scheme) to investigate data obtained from studies looking at the prevention of eczema, including the [BEEP study](#). This is linked to the project discussed by Dr Maeve Kelleher at the September Patient Panel meeting and will look at comparing individual patient data from different clinical trials to make the best use of information that is already available and so help to prevent research wastage.

Lichen sclerosus—the 2018 UK Dermatology Clinical Trials Network Themed Call (10K) has been awarded to a study team developing outcome measures for lichen sclerosus. This international project, led by Dr Rosalind Simpson (Nottingham), will develop measures for use in future studies.

New Online Course : Public Reviewing for National Institute for Health Research

In addition to the support that you all give in helping to develop and deliver the research that goes on here at CEBD, there are many people that get involved in reviewing the funding applications submitted to the NIHR from a patient and public perspective. All the NIHR funding awards outlined above will have been reviewed in this way.

To support those involved in such activities, the NIHR have just launched a [new online training course](#) which covers reviewing in all contexts for NIHR research funding programmes, plus skills and activities required at different levels and stages of research. Although primarily designed for patient and public contributors who are NIHR committee members and public reviewers, the modules include really useful summaries about the NIHR, patient involvement, the research lifecycle, and what to consider when reviewing study documents, and so should be useful for all those of you actively involved in CEBD research projects. Please do take a look and make good use of these resources.

Cochrane—Wikipedia Partnership

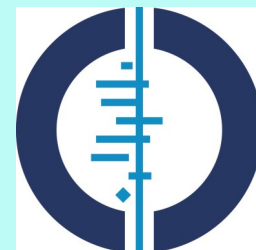
What do you do if you have a health concern? For many people their first instinct is to look on the internet, and Wikipedia results are among the top web pages returned when people search to find out about a specific condition. [The Cochrane-Wikipedia Partnership](#) was initiated in 2014 with the goal of ensuring evidence-based health-related content is shared on Wikipedia. Cochrane Review Groups, Centres and Fields engage with Wikipedia to develop more editors and share high-quality Cochrane Review evidence in Wikipedia articles.

[Cochrane Skin](#) (editorial base homed within CEBD) got involved in May 2018 when Joint Co-ordinating editor Bob Dellavalle (University of Colorado) recruited some medical students from US medical schools. Student editors were provided with instructional resources and a Wikipedia editing expert mentor, and they found that it was a valuable learning activity for their studies or research. By the end of July, all current Cochrane Dermatology reviews were incorporated into Wikipedia

articles, with 40 Wikipedia articles edited to include Cochrane Skin reviews. The work has been co-ordinated by Olivia Hutton, an MD Candidate at the University of Colorado School of Medicine. The plan is for student editors to continue to update Wikipedia when we publish new reviews, or updates where conclusions are changed.

The project has delivered high-quality, accessible material that reaches a wide audience. There have been just over 9 million views of edited articles since May 2018. Future directions of the initiative include an expansion to include more trainees, and working to improve skin-related Wikipedia content in other languages such as Spanish.

To find out how you can get involved in Cochrane please visit the [Cochrane consumer website](#) or get in touch with us here at CEBD. For more information about how to edit and improve Cochrane articles, please visit the [training](#)



Patient and Public Involvement in the Publication of Research in Scientific Journals

The importance of patient and public involvement in research is now starting to be reflected in the publication of research results in scientific journals. The National Institute for Health Research have recently adopted the [GRIPP 2 reporting guidance](#), an evidence-based, robust and practical guide to support and encourage better reporting of how patients and the public have been involved in studies. This means that all reports of NIHR-funded projects should explain how patients and the public have been involved in the study outside of being study participants/research subjects.

The BMJ have been instrumental in driving this forward and have some [excellent initiatives](#), including patient reviewers, various types of patient-led articles (including 'What your patient is thinking'), blogs and patient involvement in the editorial board, along with a declaration of patient involvement for published studies. Bearing this in mind, the [British Journal of Dermatology](#) has recently established a Steering Committee to look at how to best involve patients and the public in its activities and to build on initiatives such as their [Plain Language Summaries](#), which are freely accessible and have been published since January 2014. CEBD Patient Panel member Carolyn Hughes is part of this group and Carron Layfield (who co-ordinates the panel) is also involved so we will keep you updated of how this progresses.

Other things of interest.....

- Videos from the eczema experts Q&A panel session delivered by CEBD and the [Nottingham Support Group for Carers of Children with Eczema](#) as part of National Eczema Week in September are now available on You Tube. Please see <https://tinyurl.com/Eczema2018>
- The 2017-18 CEBD Impact Report will be available soon — [please let us know](#) if you'd like a hard copy sending out to you
- If you or someone you know has eczema, don't forget the [POEM App](#) is an excellent way to track your eczema
- [Global skin](#) (a not for profit international alliance of dermatology patient groups) has recently launched [AltogetherEczema](#)—a global on-line community for those affected by eczema